

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

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Dealing with Change

PETER LINDSAY

In the early seventies, in his book, *Future Shock*, Alvin Toffler predicted that change, not constancy, is to be our future. The world is constantly changing. To survive, we will have to change right along with it. No longer will we be able to get all the schooling we would need in the first fifteen to twenty years of our life, then go out and work for the same company the rest of our lives. Learning will be a lifelong affair. My father went to work at 21 after university and stayed with the same company the rest of his life. My son will work for many different companies during his lifetime. Change is to be the norm. Constancy is the thing that is unusual, an illusion, ephemeral.

A few years later, Gail Sheehy took up the same issue in her best selling series of books dealing with "passages". According to Sheehy, each decade in our lives brings new demands and a different set of challenges. Like Toffler, Sheehy's message is that change is an inevitable part of the human condition so we must deal with it. The way we deal with these changes can be either positive or negative. They can stimulate us to new efforts and a renewal in our lives. Or they can lead to depression and ultimately destroy our ability to respond.

Hans Seyle, a prominent Canadian neurosurgeon, entered the discussion with a sobering note. Based on his analysis of the physiological effects of dealing with change, Seyle noted that dealing with any kind of change induces a stress response in our bodies. This happens regardless of the nature of the change. Positive changes (e.g. getting married, buying a new house) can have just as much impact on our health as negative changes (e.g. losing your job, the death of a family member). Moreover, the stress effects of changes are additive at any given time and cumulate

over our lifetime. This cumulated stress can eventually make us physiologically vulnerable to disease, heart attacks, and other kinds of physiological breakdown.

According to a number of prominent writers then, the way we deal with change can be positive or negative. It is inevitable, however, so deal with it we must.

Dealing with changing technology

In modern times, one of the things that is forcing us all to deal with change is the constant and rapid change in the technology that surrounds us. This has particularly profound effects on users of AAC technology. We seem to be constantly wanting to improve the communication technology available for AAC users. We believe that improvements in the technology will improve the quality of their communication and their opportunity to do so. But don't all these changes in technology have a cost?

For the AAC user, changing technology certainly means added work and stress as they struggle to learn yet another new system. Note in Nola Millin's article in this issue, change is not without cost. Nola talks about having to give up a perfectly good and highly functional phone communication system in order to take advantage of upgrades to her computer operating system. Was the upgrade a good investment in time and energy when she had to give up something that was working perfectly well? Unlike many of these situations, at least it was her choice. It was not thrust upon her by over zealous professionals.

We too have to plead guilty in this continuous effort to provide better technology to enhance the communication opportunities of AAC users, even though we know well the risks. A recent dream of ours has been to find ways to provide access for AAC users to the worldwide communication opportunities offered by the Internet. The Internet offers exciting new communication

opportunities to all of us. Should not AAC users also be able to take advantage of it? Over the past five years or so, we have been developing a communications program called BlissInternet. This program is intended to allow persons who use Bliss to be able to communicate with other Bliss users anywhere in the world in a simple transparent way.

Clearly the goal of providing enhanced worldwide communication opportunities to AAC users is a worthy one to pursue. Actually attempting to implement this dream however has been enormously frustrating not only for us, but also for the developers and the users. The reasons for this frustration seem to be common to all sorts of technology induced advances in the AAC fields and so is instructive to consider.

First of all, unlike the large computer corporations, most non-profit volunteer based organizations that want to provide software for those with disabilities can't afford the millions of dollars that is needed to develop commercially viable products in a reasonable period of time. This means that a great deal of the professional's time has to be spent writing proposals trying to raise the support money needed rather than focussing on the communication needs that should be met. Moreover, because of the limited funds, volunteer or student programmers frequently must be relied on. These people are usually busy at many other tasks and hence take a long time to complete a project. Often they must be changed in mid-stream and hence a lot of time must be spent in learning what others have already done.

Second, the technology surrounding AAC programs is itself rapidly and continuously changing. This means that constant updates are needed even when the AAC product is finally "finished"

and perfectly functional. Just as the BlissInternet software was up and running under the Windows 3.1 operating system, Windows 95 was released. BlissInternet had to be reprogrammed. Fortunately the recent release of Windows 98 has not destroyed the usefulness of the Windows 95 version that is finally out.

Third, often we attempt to add new technology to a user's system that is already stretched to its limits or is using outdated operating systems. In fact, the new program can sometimes be the thing that finally breaks the camel's back. It can end up causing frustrating breakdowns in a system that had previously been quite functional.

Quite apart from the complexities of developing and implementing new technology, the clinicians who are responsible for recommending it and teaching the user how to use it are also trying to cope with larger and larger workloads. Typically clinicians are having enormous difficulties responding to their huge case loads and long waiting lists let alone having to try also to keep current with constantly changing technology. Moreover, as we have discussed in previous issues, the expertise of clinicians should be in understanding and teaching about communication not in the technology of AAC devices. Many feel quite rightly that being a technician is not the appropriate mandate for them.

These then are some of the general conceptual and practical issues related to dealing with change. Let us turn now to what our contributors have to share about their personal experiences.

Geb Verburg's submission, *Permanence in a World of Change*, was so provocative this time that we thought it would make an excellent beginning to our consideration of the theme. Geb takes us on a wide ranging discussion starting with the theories of Piaget and ending with a warning about the dangers of the impending globalization. In spite of his skepticism, Geb does close on a positive note — that we can all prosper in the face of even very threatening change if we

can learn to "construct positive permanence out of unruly change."

The two contributions in our new *Poet's Corner* offer different perspectives on change. The section editor, James Stuart in his poem, suggests that we confront change more directly — "I like to push push push". Alison Farmer, on the other hand, reminds us that in dealing with changing technology, we may have to deal with a new language as well.

Nola Millin provides us with an interesting personal perspective into the issue of change. Congratulations to Nola in embarking on her new business. Unlike many of us, she does not seem to be daunted by the new learning that she must do. To the contrary, the new challenges seems to be enlivening and enriching her life.

Although *The Way I See it*, by David Stow, was not written specifically to address the issue of dealing with change, it certainly reflects what appears to be a life of constant change. Most of it, at least as recalled by David, seems to have been positive. We learn how change brought him new opportunities to progress and improve the quality of his life.

Cheryl MacDonald reports a remarkable saga, first defining what seems to be an impossible dream — becoming a teacher — then going out and achieving it. She credits changing technology as making it possible for her to achieve her dreams.

Barbara Collier describes a program she designed and implemented for helping AAC users learn how to direct their own attendant care. This is a critically important issue for the quality of life of people who use AAC and we are grateful to Barbara for describing her program.

An undercurrent in the contributions of Alda Steprans, Steve Hanlon and Audrey McGee is the crucial importance of feeling comfortable in the place where one lives and of enjoying the people one is living with.

In *My Two Shadows*, Paul Marshall brings a spiritual perspective into the

discussion of dealing with change. He reminds us that we don't have to be constantly buffeted by change. We can rely on our spirit "shadow" which is enduring and stable in spite of the superficial changes all around us.

Finally, Shirley McNaughton offers her ideas about evaluating the ways in which individuals deal with changes in their AAC systems.

For our cover, we decided to use a collage of pictures of the Associate Editors from the past and present to represent permanence in the face of change. You can see how we all have changed on the outside even though we believe we have changed much less in spirit.

As always, we really appreciate your feedback on the topics we cover and the ways we cover them. Remember that we have just obtained our own domain name. **ComTog OnLine** can now be found at:

[<http://www.comtog.net>](http://www.comtog.net).

References

Gail Sheehy (1995). *New Passages: Mapping Your Life Across Time*. New York: Random House

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Hans Seyle (1978). *The Stress of Life*. New York: McGraw Hill

We are pleased to include in each issue of **Communicating Together** information regarding two new ISAAC-affiliated publications. See also page 23.

ISAAC Israel Newsletter

The ISAAC Israel Newsletter is published annually in the spring in Hebrew with English abstracts.

Rate to ISAAC members:

Regular mail: \$20.00 US

Airmail: \$25.00 US

Permanence in a World of Change

GEB VERBURG



Geb Verburg

This article is supposed to be about change, and I will get to change eventually. First, I need to express an observation which, I'm sure, you've all sensed already. For some time now, it has been popular to applaud change as a way of improving the way we do things. Maybe it began with the "Continuous Improvement(CI)" notions from the Quality Assurance (QA) era. Unlike CI and QA however, this insidious notion that change is positive has not yet disappeared. We still cling to the hope that change will somehow turn out to be for the good, some way. I suggest that you give up those hopes, for the following reason. Change in itself is merely a form of movement, flux. And you know how it is with movement: "If you don't know where you want to go you are probably wasting your energy." I have a feeling that much change lacks definite direction, and the change that is directed, has been usurped by management consultants and big business to justify

pushing through employment conditions that, in normal times, would be considered inhumane or antisocial. So change, which euphemistically might be perceived as constructive movement, has become in my mind another tool of capitalist oppression. There are probably still instances of change that are good since the instability that is created can help to dislodge a seriously stuck state of being. But change as a cult, change as a slogan, even change as a vision is not worth pursuing. If you do not agree, please look back and ask yourself (if you are too young, ask someone older) about the pace, purpose, and pleasures of life now, compared to even as little as 20 years ago.

Personally, I am much more enthralled by permanence, and so I will talk about permanence first and then come back to a number of small but important changes. Finally, I will come to a full stop at the two monster changes that are repainting our world, redefining our world view, reforming our culture, and reshaping our lives.

Permanence

Piaget's concept of permanence is, in my opinion, still one of the most intellectually satisfying descriptions of the development of knowledge. In it, the infant and his or her world gradually acquires permanence, shape, stability, and meaning as knowledge of the world develops. Objects continue to exist even when he or she can't see them. Knowing and learning is then defined as a process that starts at the intersection of person and world and progresses from that point outward and inward. In moving outward, it develops "knowledge of things" and the inward development creates "things known" at the exact same time.

Beginning with permanence of objects, in which things acquire boundaries and independent identities, Piaget

continues to explore permanence of size, width, number, volume, mass, and many other phenomena. The world which was undifferentiated for the infant gradually acquires boundaries, substance, permanence, shape, identity, names, and properties. In short, it becomes the world that we all live in and share. The process of permanence acquisition never stops. We keep finding new things that acquire boundaries, shapes, properties, names, relations, structures, etc. As we build this new knowledge, the world as we know it changes at the same time.

I hope and believe that we will learn to identify what is permanent and what is worth holding onto in this rapidly changing world of today. We seem to have acquired a massive expertise of things physical. I wonder if we are paying enough attention to the permanency that exist in our interpersonal, social, emotional, and cultural lives. These too are worth identifying, rendering permanent by naming, and symbolizing and thus making them part of our public knowledge.

Some Small Changes

I want to highlight a number of items or stories from the Bloorview MacMillan Centre's newsletter called "Sites and Sounds" because they represent changes that have happened in the field. The first of these articles was called "Sharing 'bad news' with parents". It discusses the importance of the way in which news that may be devastating to parents is delivered. The article points out that it is essential to "engage in honest, adult-to-adult communication that is supportive of parents and supportive of the parent child interaction". The authors argue that it is crucial to give the parents control over the process of receiving information. What I found most significant about this article was that it was based on interviews with our medical director (Dr.

Peter Rosenbaum) and one of our physician directors (Dr. Peter Rumney). I am sure that both of them will argue that physicians have long since known how to communicate sensitively with parents and clients and have done so for even longer. Yet, for me this was the first time that I saw our own physicians express in a public forum a holistic and sensitive approach to a very important and all too common issue, i.e. how to bring bad news to parents.

A second story in the newsletter talked about two members of the family advisory council who took the initiative to attend orientation sessions for new staff. They felt that they could make suggestions to staff to help staff make visits to Bloorview MacMillan less stressful for parents and families. Some of these suggestions:

- Smile and introduce yourself;
- Take the time to truly listen to a parent's questions;
- If a parent appears lost or confused, offer to direct them;
- Speak to the families the way you would like to be spoken to;
- Show respect by apologizing if you are late for an appointment;
- Put yourself in the family's shoes and try to empathize.

"We don't want that pitying look. We want empathy."

These two stories are hardly earth-shaking. Many issues ago we spoke about empowering parents and clients. And even more years ago I wrote about professionals and about ways in which clients and parents could learn to "handle" or collaborate with professionals. We have also addressed attitudes toward clients that left much to be desired. In one way it is nice to see that these topics are now advocated in the "Sites and Sounds" newsletter. On the other hand, it is too bad that it seems to be necessary to teach new staff such straight forward rules of communication with clients and parents. Apparently they have to be

reminded to use common civility, not just courtesy and to treat parents and clients as partners with respect and empathy. One would expect that the schools and universities that are training these professionals would have picked up on that by now.

Other small changes.

Another example of a small change is a weekly half-hour magazine style TV program about people with disabilities on the Canadian Broadcasting Corporation network. Somewhat disappointingly, this program proudly advertises itself as "the only show of its kind in North America". For detailed information on the program, see http://www.tv.cbc.ca/moving_on/. It contains interesting features such as: "Job Fair", "Tales from the Crips", "Deep Inside" and others.

Another recent positive initiative is called Reach. This is a pilot project from the Alternative Resource Corporation and Information Technology staffing and service firm. This firm provides help-desk services for large companies. The Reach program seeks out people with disabilities who can be trained to perform help-desk functions. More information about this program can be found at: <http://www.alrc.com/>.

If one were inclined to be cynical, one might think that this was too good to be true. Maybe it is just a modern version of the sweat shop. It is important to be sure that it is not like one of those telephone marketing jobs that does not have any regulations or security, that has no pension or even a fixed salary. These reservations aside, it is nice to see a company looking for employees in the *entire* workforce.

Finally, the National Institute of Disability Management and Research (NIDMAR) has produced a new video called "*The Challenge to Lead*". This video documents the recent growth of workplace-based disability management programs across Canada. I will quote a little from the email that I received.

"This proven return-to-work model for injured and disabled workers is meeting with growing support from labour, corporate, and government leaders. Disability management has become an increasingly positive force in the Canadian marketplace. It is a strategy that produces not only better workplace environments, but also social and economic benefits."

These comments are followed by an impressive list of government officials (minister, premier), presidents, and CEOs who are supporting it. The video costs \$79.95! You can order it or get more information from Ms. Julie Steven (email: <steven@nic.bc.ca>). Personally I have trouble with the term "Disability Management". But then I even balk at "Labour Management" and go practically bananas when I get one of these dumb brochures that purports to show you "How to Manage Difficult People". (I strongly identify with DPs.) But let me not get too petty.

NIDMAR has recently signed a Memorandum of Understanding with the International Labour Organization. This is expected to lead to the first ILO Code of Practice in Disability Management. This code of practice in turn will provide guidelines to workplaces and ensure fair and equal treatment for workers with disabilities around the world. That sounds like positive change to me. I hope it works.

A Monster Change

In the Fall issue of **Communicating Together**, 1998, I wrote about economic development, globalization, restructuring and all the people who already have or who are about to lose their jobs because of automation, restructuring and globalization. I came across William Greider's book *One World, Ready or Not: The manic logic of global capitalism*. This falls under the accidental encounters with impeccable sources. Greider is

the national editor of *Rolling Stone* magazine. I am not nearly as optimistic as Greider about the capabilities of national governments vis-a-vis supernationals. But he presents an idea that is very relevant which has to do with our (i.e. people's) preparedness to deal with the insensitivities, I should probably say the brutalities and inhumanities of the Global Market.

Greider suggests that we should not simply let globalization devour the world like a rudderless monster that is out of control. Rather, we should do the work we need to do to get ready for this new world.

Globalization, in my opinion, is a cancerous growth with all the evil and malignancy of that disease. The driving motives underlying globalization are power and greed. I cannot imagine a more unholy alliance. My childhood family pastor would conjure up images of Beelzebub and Mammon to represent evils such as power and greed. While these characters have hardly any currency anymore, I cannot think of worse hands in which to place the future of our world. Obviously, I do not see globalization as a positive change.

Even though there are many doubters, we are all encouraged to believe that globalization is unavoidable. Certainly we will all have deal with it. It does have some potentially positive aspects but we are still very far from realizing those. Qualitatively, globalization is so much worse than Socialism, Marxism, or Communism, all of which, at least in principal, held ideals in which people played a part. Globalization does not even have the cosiness of the Global Village concept of the late Marshall McLuhan. As I see it, globalization has no morals, no values, no ethics, and no role for people other than to consume. I don't believe that I have ever hoped more vehemently to be wrong about something.

So what does Greider suggest we do about it?

Industrial growth requires two things: raw materials and evermore consumers. Raw materials is a devaluing name for the Earth's limited resources. An inherent belief of capitalism is that production and profits must continue to grow. That this growth happens at the expense of dwindling resources of a limited Earth does not appear to worry industrialists. Greider explores a number of concepts and approaches aimed at changing these attitudes in order to replace them with an appreciation of the "common good". He argues that since everybody will be affected by the globalization of production and consumption with their concomitant pollution and waste, everyone will realize that "we are all in this together". This sense of us all being part of a planet that cannot possibly sustain the industrial attitude of wasteful despoliation of resources should unite us and create a new ideology. Greider's hope is that this new ideology, perhaps a new form of global humanism that he feels is emerging, may be able to reign in the runaway globalization.

The other monster change is actually a subplot in the globalization scheme. It is called telecommunication or multimedia connectivity or something longer and more confusing. What it stands for are all the capabilities of multimedia communication and information exchange rolled into something as small as a portable telephone or a pocket organizer.

The power of these new capabilities is so awesome and daunting, and, yes, also so fantastically beautiful, that at the moment, I am almost at a loss as to how to evaluate it. I think it is very important to remember that multimedia telematics (i.e. telecommunication and informatics technologies) are a tool first and foremost. Moreover, they are tools that can be used for good and for harm. At the moment many people are expecting too

much of the old things (power and greed) from it. Business expects it to allow it to make massive amounts of money (through e-commerce), government expects that telematics will create thousands and thousands of new jobs for all the destructured employees, students expect that they can become smart without studying, parents expect their offspring will become even greater geniuses with the help of telematics. What the tools really will deliver is very far from obvious as yet.

Within remote rehabilitation, education of parents and clients and in telehealth in general there are amazing opportunities for telematics applications. I consider myself to be fortunate to be able to be working on some of these applications. And I am optimistic that overall, they can have a positive impact on families with children who need AAC or rehabilitation. They can also benefit community professionals who work with the children and families. I am far from being a Luddite. As you can tell by now, I am skeptical about change but trying to find something positive within my often critical perspective.

Change is something to keep an eye on.

What is much more important than change is our ability to construct positive permanence out of unruly change. We could call it learning, or growth, or personal development. This is a skill that we need to cultivate not just in people with disabilities but in all people, young and old, rich or poor, near or far. If all goes right, we will. After all, we will all be living on the same small planet for some time to come.

§

Reference

Greider, William. (1997) *One World, Ready or Not: The Manic Logic of Global Capitalism*. Simon & Schuster, New York. ISBN (hard cover) 0-684-81141-3

JAMES STUART

Change

Here we are in this world of change
Where everything is constantly changing
But it seems like the more it changes
The harder everything seems to get.

People have said that we're moving too quickly
They tell me that I should maybe slow things down
I think that things are moving too slow right now.

Maybe I should just take it easy, let things go.

But that's not my way, I like to push, push, push
Swinging deals and making compromises when I must
Meeting a few strangers, making some new friends
Causing everything to keep right on changing.

Keep right on progressing with time as it passes
Maybe things will get just a little harder
But I think that if we stick together
We can handle anything that may come our way.

James Stuart

We are pleased to have a contribution from Alison Farmer for this, the second issue of Poet's corner. Alison resides in Hamilton, Ontario. She is a highly motivated entrepreneur and is currently developing a business plan and career portfolio to further her employment in personal services for the elderly. On a personal level, she enjoys her pet and travelling.

So much can be said through poetry! If you have a poem you would like to share with our readers, please send it to me by snail mail or email:

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Computer Technology

C is for **COMPUTER**
O is for **OBSTACLE REMOVER**
M is for **MOTHER BOARD MACHINE**
P is for **PROGRAMS**
U is for **UNBELIEVABLE**
T is for **TECHNOLOGY**
E is for **ELECTRONIC FILING**
R is for **RESOLUTION**

T is for **TOGGLING**
E is for **ESCAPE KEY**
C is for **COMPUTER CHIP**
H is for **HARDWARE**
N is for **"THE NET"**
O is for **ONLINE**
L is for **LICENCE**
O is for **OBSOLETE**
G is for **COMPUTER GURU**
Y is for **YAHOO INTERNET SERVICE**

What have you spelled?
Computer Technology!

Alison Farmer

Re ComTog OnLine

You will notice that the banner on our cover contains the new address for our **ComTog OnLine** website — <http://www.comtog.net>. We had to change our address because we needed to change our Internet Service Provider. A notice to all **ComTog OnLine** subscribers informing them of the pending change was included in the last issue of **Communicating Together**. We apologize for the disruption of access while arrangements were being made. For those who wish to browse and explore a sample of the online issue, we invite you to check out our new website. Furthermore, questions can now be addressed to: <information@comtog.net>.

Facing Changes

NOLA MILLIN



Nola Millin

Dealing with Professionals

First, there are the professionals that I have dealt with. I can't count how many physiotherapists, occupational therapists, and speech pathologists I've had over the years. Although this is a fact of life, it can still be difficult to accept that I'm going to have another new therapist. I don't develop personal relationships with each individual who is providing a service to me but I get used to dealing with a specific person. When the professional gets to know my needs, abilities, and even my personality they are able to understand "what makes me tick."

The following story has been told in other issues of **Communicating Together** but it illustrates this very point so it's worth repeating. Tracy Shepherd used to be my speech pathologist and knew me fairly well. She felt a laptop computer hooked up to a multi-voice would probably work for me. Without telling me, she brought a laptop computer and a multi-voice and showed me the basics of how it worked. Then she left! You have to understand that Tracy knew me well enough to know I would try using the device if she didn't push it on me. Tracy gave me her home number since it was a weekend and said to call her if I couldn't figure something out. By the way, Tracy was right to introduce the laptop to me. I now use a laptop computer hooked to a multi-voice as one of my more important communication devices. That change has had a very positive effect on my life. I deliver presentations with my voice output communication device.

I think about that story and compare it to my childhood and teenage years. During my earlier days, I felt as though I was switched from therapist to therapist every six months. That was a common practice 20 to 30 years ago. I hope things have changed now.

As an adult, I'm able to accept the change of a therapist easier. Sometimes it isn't easy to see someone leave and then have to get acquainted with another individual. As an adult, however, it's easier to understand. As a youngster, I don't remember being told what was happening. I remember being with therapist "A" for months then suddenly therapist "B" would take over. No one would offer an explanation. I also remember therapists getting mad at me because I would be "uncooperative" with them for the first few days after they had taken over my therapy. It was like it hadn't occurred to them that things would have been a lot easier for both of us if they had spent the first therapy session allowing me to get to know them.

Services of Others

I have been using therapists in my examples but this same principle happens in any situation where the person with a disability relies on the services of others. I see it in the building where I live. There is 24-hour-a-day attendant care staff in the building. The staff turnover is phenomenal. New staff goes through the normal training procedures and then they observe the way the experienced staff does our care for a few days. I find this period

It is pretty safe to say that everyone faces change throughout his or her life. I'm reminded of the saying that goes, "Change is inevitable except from vending machines." Change comes in all shapes and forms and affects our lives differently at different times. I really feel that change helps each individual to improve their self image if they accept the change. Obviously, individuals who have physical disabilities aren't protected from dealing with change. In fact I think that people with disabilities might face more change in their lives than able-bodied persons. I realize that some readers will disagree with that statement, which is fine. But allow me to explain my reasoning by using examples from my own life.

difficult. Here are these new people that I've only met once or twice and suddenly they're seeing me in my birthday suit. I certainly realize part of their job is to assist me in dressing. Even so, it's not easy allowing someone you don't even know to see you without clothes.

There's also an awkwardness with new staff even if they're only cooking a meal for me. Although each tenant is supposed to give the staff directions, the experienced staff sort of know what each tenant likes and where things are kept. I sometimes find after a new staff member has done my care that I feel exhausted because I've had to tell the person each step of the procedure. There is also the fact that the staff who have been here longer can understand my speech but with new staff I have to rely more on my communication devices. Although it's awkward and trying at times, I frequently get the new staff because I'm told that I'm one tenant who is able to direct and work with a new person in a pleasant manner. Apparently, somewhere along the way I have learned how to make a new person feel comfortable, or so they say.

Dealing with Changing Technology

There are certainly other kinds of changes that we experience. One is the change in technology. It is obvious that everyone experiences this change. The problem I've found is even though new technology is supposed to be better and perform faster, sometimes the adaptive aids don't work with it. I have had this problem many times. For example, I use to have a phone communicator. Unfortunately, they stopped making phone communicators so when I upgraded my computer to a faster processor, I was no longer able to

use my phone communicator. It had been created for a slower processor. It was a very frustrating time for me because I was extremely happy with the phone communicator. Like everyone else however, I wanted a faster computer that could handle newer software. The only thing I could have done was leave my obsolete computer set up with my phone communicator in it and set up my newer computer beside it. I have an one bedroom apartment so having two desktop computers set up wouldn't have been practical.

I ended up having to develop a whole new method for talking on the phone. I now have a set of speakers hooked up to my multi-voice and people seem to be able to understand what I say. My new method does work but my old phone communicator was much more efficient. It had certain functions built right into it that made phone communication simple for me. The bottom line is that sometimes advancements in technology can cause even more hardship for individuals with disabilities and these changes are very frustrating.

Up until now I've been talking about the changes I've faced mainly because I have a disability. I want to switch my focus a bit and tell you what changes I have experienced despite the fact I'm disabled. It is common for people in this day and age to make dramatic changes when they are more mature. I am not any different.

Starting a New Business

Recently, I started my own business, which has been a major change for me. I mentioned my business in my last article. For the remainder of this article I'm going to talk about how my business came about and how the need for change was a motivating factor.

About three years ago I went through a period of depression. I had been out of university for a few years and I had just finished a two-year major battle within the building where I live. I was also going through some personal struggles. I felt like suddenly there was nothing in my life for me to do during the day. I also felt lonely. Looking back on it, it made sense that I felt lonely. I was no longer attending nearly as many meetings or doing things.

I finally applied to a sheltered workshop for people who have physical disabilities. For a while, this workshop fulfilled my need for change. I was able to get out of my apartment a couple of days a week and be with others. As I recovered from my depression, I started liking the workshop less and less. The work wasn't in any way challenging. One of the staff at the workshop began telling me about a new program that he was involved in. The program is now known as Opportunities Fund. Part of the program is to finance the start-up costs so a person with a disability can have a business. When I first heard about it, my initial reaction was to think I couldn't run a business. I didn't have a business mind and I didn't have an idea of what type of business I could do. Although I was bored, I was still complacent. I feel complacency can be very dangerous because when I get complacent, I tend to avoid any opportunities to change. I wasn't going to consider the idea of becoming self-employed. One day, some time later, another person mentioned the Opportunities Fund to me again. That time I was open at least to looking at it so I applied. I still wasn't sure what type of business I would do. Something inside however made me realize that I was already doing two things I really

enjoyed. One was my speaking engagements. The other was desktop publishing. I attended the three-week discovery workshop that everyone who applied to the self-employment aspect of Opportunities Fund had to take.

The course helped me to discover that self-employment was definitely what I wanted to do. A friend introduced me to the idea of including multimedia editing in my business plan. Multimedia editing includes editing videotapes, converting records to C.D.'s, and photo retouching. Coming up with a business plan was difficult but convincing myself I could earn an income was the hardest part. So, my business plan is actually all of these things. I do speaking engagements and I do multimedia editing.

One of my biggest fears about having my own business was the fact that I didn't have any experience with running a business. Fortunately, the Opportunities Fund Program had anticipated this and they solicited the help of the Self-Employment Assistance Program. This program worked with people on unemployment insurance. Their main goal is to teach people skills that are needed to run a business. I attended a four-day course on how to put a business plan together. I didn't have any idea of what was needed in a business plan, but I knew I had to submit one in order to get assistance from Opportunities Fund. Once my business plan was accepted, I attended a four-week course offered by the Self-Employment Assistance Program. That course really helped me because it taught the basics of marketing, bookkeeping, and legal matters. One nice part about the SEA program is that I will continue to get assistance from them for an entire year. The people in the office are available to

me. They help me build my business by providing advice and suggestions. Mind you, it's still my business. I can't sit back and expect the work to be done for me. It is good however to have people I can turn to when I need help.

Having my own business has meant a lot of changes in my life. Yes, it is a positive change, but it was still change. After taking the Discovery Workshop I quit working at the sheltered workshop. I realized that because I was surrounded with positive people who saw my potential, I started seeing my potential. I saw a definite change in my attitude. I'm faced with many challenges, which I like because they keep my mind active. A change in the people I associate with has also occurred. Of course, I still have my many friends but I now have business associates who are valuable. A change has also happened in how my time is spent. During my depression, I would spend countless hours in front of the

T.V.. Now I hardly watch any T.V. at all. I'm usually working on a speech or I'm doing something that a customer is paying me to do. I have a whole new focus in life.

As I look back over some of these changes, especially the ones during this last year, I'm grateful for them. Despite the fact that some changes are negative and others are positive, they have all helped me to grow and to develop. I know now that change allows me to discover new things. When I deal with the change of a therapist or of an attendant, I develop better social skills as I try to be patient with the new person. As I deal with new technology, I find that I quickly learn how to be innovative in order to make the technology work for me. These changes help to prepare me for a few of the challenges I will face in the business world. Although I don't always like change, I can see how changes in my life have always improved my self-esteem and made me feel better about myself in the long run.

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The Way I See It

DAVID STOW

One of the delights of the ISAAC Conference in Dublin last summer was meeting David Stow, a young AAC user who receives his AAC support from the ACE Centre, Oxford, England. We received David's permission to print the presentation he made at the conference, and have decided to include it within our Perspective section. We hope you will enjoy reading what David has to say.

Hello everyone. I think you know my name is David and I was 14 last month. As you can see, I am in an electric wheelchair which is really great now. I can drive around and talk, but it hasn't always been like this.

I was two years old when I came to live with my family and I was a pretty unhappy person. I was sad because I didn't like what was happening to me. This was my sixth home and I was upset because I didn't know what was going on and I'd had a pretty difficult time in my previous placement. I was frightened and angry. In fact, I'm told that I used to hold my breath and go blue in the face and then grey. I frightened my new family half to death, too. The consultant told Mum that I would always breathe again but she said it seemed to take an awfully long time. My new family seemed OK. After a time, I even began to feel safe with them. I think now, looking back, that love had something to do with that. I'd gained a Mum and Dad and three brothers and two sisters. They had been told that I wouldn't ever learn anything because my brain was too damaged. Fortunately for me,

they couldn't agree with this. One day, after I'd been with them for some months, Mum asked me if I could see a window. It took me ages to get my head round but when I found it she says my eyes sparkled. Then she asked me to find the television and I did. Then, wherever we were, Mum or Dad would ask me if there was a clock or a window. One day, we showed the consultant that I could do this, so he said I had to be educated. Wowee!

"The best switches are no good unless you've got the right computer, and that's no good without the right software, and none of it is any good without the right teacher. And so it goes on. Life is never dull or routine!"

After this I went to several different play groups at the hospital. When I was three, I started at my first school. This was a small unit attached to our local hospital and it seemed I had a lot to learn. The people there seemed to think that I could. The days of being a vegetable were gone. We met all the usual difficulties with seating, equipment and feeding and all the rest of it. It was at the Kestrel Unit that I started using the Bliss symbol language. They gave me two flash cards with Blissymbols, one of which said "Yes" and the other "No". Suddenly I could have a say about what happened. I could make choices. This was good.

When I was about four, Mrs. Gibbs arranged for me to go to the ACE Centre in Oxford with Mum and Dad and my teacher. Mum and Dad reckon this was one of the most

important days in my life because that's where I first met a computer. When we got there, I was put in front of a computer and given a hand switch and told that if I pressed it, something would happen. And it did. I made lots of things happen and then I was given a second switch to use with my head. Now I could really show that I understood and knew what I was doing. I've got a bit of video that was taken that day.

I stayed at my first school for about three years. I really had a good time there and learned a lot. Then I had to go on to a bigger place where there were more children and facilities — more physiotherapy, speech therapy and so on. It was OK at first. I made some good friends and had a good teacher. But later on, my technology seemed to cause a bit of a problem. I was using a Real Voice and Scanpac at this time and it had to be set up on my chair, plugged in and switched on for me. Somehow, things didn't always seem to come together. Sometimes it was fixed on my chair, but it wasn't switched on. At other times, my Real Voice was switched on but my switches weren't plugged in. I suppose I just didn't "click" with some of the staff at the school, but I did resent being thought stupid. It's very difficult if you have sometimes to work with someone who just doesn't pick up your signals, or who just doesn't seem to expect you to do anything anyway. When this happens, after a while you get bored and fed up. What's the point of bothering when they don't understand? It's hard enough anyway.

At about this time I had to have major surgery and I was in a plaster for three months. Mum didn't think I should just hang around, so after a bit I had a home tutor. She was super. She was a retired head teacher and had

never worked with anyone with a disability before and she wasn't too sure about me. The first morning she brought some scarves in a bag and started to talk about their colours. That was fine until she brought out a blue one and said it was red. I couldn't believe it. Mum says she will never forget my face. That afternoon Mrs. Cash went into town and bought the national mathematics curriculum for my age. That was the end of my holiday. But she confirmed that I knew my letters and numbers and could read a bit.

We had an update of my educational statement which confirmed all this. The educational psychologist was brilliant. He waited until we were alone and then we talked about sport, and things on the news. He had me eye-pointing words and spelling. Of course, I got on all right with him. He was sensible. His report said lots of things about my understanding, including the fact that, although I couldn't speak in sentences, I understood very quickly whether or not someone understood me. Eventually, I moved to Victoria School in Poole.

Finding the right equipment is really important and it does take a lot of time. Sometimes, things look good in a brochure, or even when you see someone else using them, but that doesn't mean they are right for everyone! I've tried seating and wheelchairs that in theory are right for me, but in practice don't help me at all.

I've been waiting for months for my new electric wheel chair. I've outgrown my seating and it's not helping me at all at present. My physiotherapist asked for a new chair last September, but they said the one she mentioned was too expensive so they got a cheaper one, but it took them four months to get it, and then it was no good. It's really crazy. I was really angry. And so were Mum and Dad. I was in the team at school to take part in the Keilder Challenge

Cup, but I needed my new chair to do it. My old one couldn't have coped. In the end, I couldn't be on the team, and that made my physiotherapist so mad, because she wanted me on it. I wanted to be there with my friends too. We'd done all the work and preparation and I had to miss out just because the wheel chair service didn't get on with it. I thought that was really rotten, and unfair. How would they feel if they were in my place? They just don't understand.

We really have tried all sorts of equipment but I think my 8+8 and Cameleon are two of the best things. My 8 + 8 is the smaller black box in front of me. I've had it about four years now and with it, I can drive, access my Cameleon to speak (like now), use my word processor, access my painting program, games and printer. It's also got a buzzer on it, and some infra red switches, so I can switch lights on, or the radio, and I used to use it to drive my electric train. It's good. We are getting things together. The only slight problem is that at present it takes me eight seconds to get into speech mode, from driving. So, if I drive up to you, just give me time to get into speech mode!

Switches are another problem. I've tried using one or two or three! I've tried accessing them with my hands, or head, and anything else! However good they are, if I can't apply enough pressure, or if they can't be sited in the right place for me to access, they have to go! Once, I tried a new head support. It was really good. It helped me sit so well. My back was straight and my head was supported really well. The problem was, I was so well supported that I couldn't access my switches properly, to speak or drive! It caused problems getting in and out of my seating as well, but, more importantly, I need to tilt my head to access my switches and this head support just didn't allow me to do that. You could perhaps change your method of access

but I can't. And then, the best switches are no good unless you've got the right computer, and that's no good without the right software, and none of it is any good without the right teacher! And so it goes on! Life is never dull or routine!

I have to use head switches for my communication, driving, word processor and so on, but I can't operate my CD games on my desktop this way. So, when I play cricket, Mum or Dad tie the joystick onto my chair and I can wrap my arm around it, and then I can bowl. I've got a grand prix game too. One day, I told Mum, "Right side". At first, she didn't understand what I meant, but I made her understand that I wanted to access the right side of my keyboard. I knew that if I could get to the keyboard, I could control the cars, alter the settings, and the camera positions and lots more. I know what I want to do and which keys I want to press, but my fingers won't do it. Now, my wheelchair control is positioned right onto the keyboard, and I get at it with my right hand because that is my best side. It's good fun. You've just got to do as much as you can. Any way you can!

I've got about eighty-eight pages on my Cameleon at present. A lot of them are really useful and have preprogrammed sentences — the sort of things I use a lot — about food, things I want to do, places I need to go, that sort of thing. I've got a "social" page that's useful when I meet new people. It includes typical phrases that are useful in a social situation like "What's your name? Where do you live? What do you like doing?". My real interest is sport so I've got a whole page for Grand Prix racing, premiere league football and general sport as well! In June, Mum added a really useful page! It was entirely about the World Cup. I could really say what I wanted!

There is no way we could program every sentence I might ever want to say, so I have pages of nouns, verbs,

describing words, feelings, colours, alphabet and so on. These are useful for making up my own sentences. When I'm doing this, I use a sort of "short hand." I'll give you an example of what I mean. If I was to build the sentence, word by word, to say "Can we go to town on Saturday?" it would mean using my head switch sixty-two times. Yes, sixty-two times! That's hard work and takes a long time. Don't worry. I don't do it. If I say "Town Saturday" it is much quicker and only takes nineteen switch movements. Guess which I say? Wouldn't you? And of course, if I sneeze when I'm saying something, that means a lot more work because I hit the switch at the wrong time and lose my place.

Just think, if we hadn't preprogrammed this talk it would have taken me the whole ISAAC Conference to talk to you! I would be exhausted and you would be dead bored. We started working on this paper in March. I told Mum what I wanted to say in my short hand and she wrote it up and then read it to me to make sure it was what I wanted to say. Then she programmed it into Cameleon for me. It took ages, but we think communication should be fun and it is, usually. I like Cameleon because I can get my point across to people and say what I want to say, not necessarily what people think I want to say. And I can argue if I don't agree. I do get mad when people don't give me time, and when they think they know what I was going to say. How can they?

I told you I can argue with people now that I have my Cameleon. One day I had an argument with Mum, and I won. I asked her if we could go to the computer shop by the bus station on Saturday and buy a new CD game for my computer. We went down and I had to decide whether I wanted a football game or a cricket game. I chose the FIFA football. It was OK but the sound wasn't really right. Something was incompatible. On the next Thursday I asked Mum if we

could go and get a new game, but she said "No", because they were too expensive and I'd just had one. I said the football game was old, but she said it wasn't. I said it was broken, but she said it wasn't really, just that the sound wasn't quite right. I said "Please, please, please," but she said "No". I really didn't think I was going to win but I suddenly remembered something else I had in my Cameleon. We had done a shopping project in our communication group at school. It was ages ago but I knew it was there. I said "Please will you take the money out of my purse?" She was so surprised that she said "Yes!" So I got Ian Botham's International Cricket Game too. It's really great!

When I was young, people didn't know whether I would be able to learn to talk or not. I wish I could, but I can't. I don't remember much about my early speech therapy but I can tell you what I do now. I have two therapy sessions. One is in a group, with five other students, and the other is on my own with Judith. In our group we play games like snakes and ladders, and noughts and crosses, anything that will help us with talking. If we're lucky, we get chocolate drops too. I enjoy the speech therapy group, but I prefer having sessions on my own because it gives me more time to talk. I like telling Judith what we have done, like when I went to Twickenham to watch rugby, or to Southampton to watch cricket. I like talking to Judith about lots of sport and other things, and Judith gives me the time. Like I said before, it takes a long time to build up sentences if they are not preprogrammed. Even so it at least lets me say what I want. I just need time and Judith gives me that. She's fun.

Last term, I designed a Grand Prix game in speech therapy. It's really good. As you go round the circuit, which is based on Silverstone, you win cards with verbs and nouns and so on. At special places on the circuit, you get a chance to use these cards to make

a sentence. Then you get round the circuit faster and win the race. Judith says she has learned a lot about the Grand Prix and football since knowing me.

So, the way I see it is as follows. People like me are all different. Some, like me, have problems with our output, but we do not have problems with input. We hear, and understand, sometimes more than we should. Some people think we are not smart and can't hear just because we are stuck in a wheelchair and can't speak like them. So often, they don't see *us*. They just see our *problems*. They see our high tech wheelchairs, our speech computers, and all the rest of it, and they don't understand. I can accept that people don't know how my equipment works. It is complicated. But I do object very much when they suggest that I am stupid when in fact it is them who don't understand. And then sometimes, they expect us to perform, just like a performing seal. We are not "actors" playing a part. We are us, not from choice, but because that's the way it is.

Now, the last two things I want to say! TIME. Give us TIME. It takes TIME to get into speech mode, TIME to scan through our set ups, TIME to get the words we want, TIME to compose our sentences, and TIME to say them. Give us that TIME and remember too, how tiring it is. Remember, sixty-two head switch presses for seven words.

Lastly, don't "talk down" to us. We are not simple. We understand, often more than people think. Physically, don't talk down to us either. You all talk face to face, with eye contact and facial expression. Why must we be different? If we're in a wheel chair, sit down, or at least, come down to our level. We don't like talking to giants!

Thanks for listening.

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Technology: Enabling Persons with Disabilities

CHERYL MacDONALD

Cheryl MacDonald is a new writer to Communicating Together. In her own words, she describes herself as: "If anything, my disability is a gift providing me with the tenacious spirit to live life to the fullest. I love walks in the park with my dog, decorating, gardening and Lake Huron sunsets. My devotion to youth is enhanced and nurtured by my relationships with my nieces and nephews. I enjoy the excitement of competition at the Canadian Electric Wheelchair Hockey Association. I also enjoy relaxing with music and poetry."

The commencement of any written work is usually the most challenging part of a writer's job. It is the "getting starting" that presents the biggest obstacle. Typically the quest for inspiration or creativity is the hurdle which must be overcome before any writer is off and running. Consider for a moment, though, the author whose problem is the exact opposite of this norm — the writer, poet and teacher who is overwhelmed with thoughts, ideas and inspiration, but lacks the physical ability to write. I am such a person. With the aid of technology however, I am able to write this article, and, to do much more.

Technology became an integral part of my life while I was in high school. It was in grade thirteen that I had my first personal computer. Finally, I was able to research, write, edit and rewrite essays much more speedily, efficiently and independently than my electric typewriter and one-fingered typing had ever allowed. Although the computer I used is now very outdated and I was still typing at the speed of an average seven-year-old, it did allow me to complete a degree in Honours English from McMaster University. English has always been my

passion. Although this course of study offered few "practical" career avenues for a young woman whose speech, mobility and motor coordination were affected by cerebral palsy, I followed my heart.

As my love for the arts was continually nurtured, so was my dream of teaching. Each summer while I took courses in order to compensate for my slightly reduced workload throughout the year, I also managed to hold a part-time job as an educational assistant at a local elementary summer school program. It was not long after graduating from university that I became employed as an educational counselor for an inner city alternative educational program affiliated with a local high school. With each new experience in the field of education, my fervour to prevail and progress intensified, and my vision of becoming a teacher grew closer to reality.

The culmination of my academic effort and employment experiences was finally rewarded in the autumn of 1994 when I was accepted into the teacher training program of Brock University's Faculty of Education. Despite my excitement and hopefulness, I knew that this endeavour would be the most challenging of my educational and professional career. The government provided me with funding for a teacher's assistant who would serve as my "hands" for such tasks as grading papers and writing on chalk boards. Even so, the daily after-hours requirements for typing reports, tests, assignments and lesson plans presented a seemingly insurmountable dilemma. It was at this time that I decided that technology would once again compensate for my physical limitations.

I had heard through word-of-mouth of a current software program that would allow me to dictate rather than type text.

Funding for the new hardware and software was approved by the appropriate government program. Within weeks, I was "typing" at more than twice my previous speed. The *Dragondictate* software was programmed to learn my speech patterns. Thus the more I used it, the faster my "typing" became. With *Dragondictate*, I could now complete tasks at a rate comparable to that of my peers.

I graduated from my teacher training program and am presently in my third year of employment as an occasional teacher (better known as a "supply" teacher) at my local school board where I work primarily at the high school. I have recently commenced a home instruction assignment through the same school board that will allow me to teach a grade ten history course. My next immediate goal is to obtain a permanent teaching position.

In terms of technology, I have recently added a scanner and an LCD projector to my computer system. The scanner will enable me to grade papers right from my computer screen. The projector will allow me to project text from the computer screen onto a larger screen which may be viewed by a room full of students. This means I can project anything that I would ordinarily put on the blackboard. Thus my technology makes it possible for me to function completely independently as a teacher.

It seems that whenever I unlock another window of dreams, technology provides me with the stepping stones I need to carry me to my desired end. Whether it be research, professional composition and projects, creativity or personal reflection, technology has always provided the kinds of supports I need to augment the mechanics of my body. My computer has taken away much of the handicap incurred by my disability.

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Learning to communicate with attendants

BARBARA COLLIER

Barbara Collier is a speech-language pathologist with over 20 years experience working with adults and children who use augmentative and alternative communication. She has worked as director of the Adult Adaptive Communication Service, Toronto, as a consultant at the Augmentative Communication Service, Bloorview MacMillan Centre, Toronto (formerly The Hugh MacMillan Centre) and as a senior consultant of service development and training with the Ontario Ministry of Health's Assistive Devices Program. Barbara is currently an independent consultant offering communication services for both agency staff and individuals.

I thought we'd start with an easy one..... nail care. I mean, surely that's pretty straight forward. Only a matter of cutting, filing, cleaning.

That was before Scott MacArthur took a deep breath, looked at the group of eight AAC users and began his two hour dissertation on the trials and tribulations of having an attendant give him a basic manicure.

Your attendant needs to know that your hand will probably clench with spasticity when the nail clippers are produced. Telling you to relax just makes it worse. Many attendants do not understand that you cannot control your spasticity... if you could you would probably be able to cut your own nails!

The AAC users listening to Scott were all nodding or lifting their eyes in agreement. He understands. Now what does he say to his attendant in this situation? For most of the AAC users, what Scott says and does in this situation could give them suggestions for vocabulary and strategies they could use.

We came together as a group, three hours each week for twelve weeks for a course entitled "Communicating with Attendants". The course was funded by the Ontario Federation for Cerebral Palsy (OFCP). There were eight AAC users, all of whom were currently using attendant services and all were eager to improve their communication with attendants. While some of their attendants (certainly not all) had received some training in how to communicate with the AAC user, the AAC users themselves had never received any specific training in how they could direct their attendant care services using their AAC systems.

I designed and presented the course but we all received invaluable input from the group facilitator, Tony Diamante. Tony is an experienced AAC user who directs his own services. The second AAC user helping with the course was Scott McArthur, the director of training at OFCP. Scott also directs his services.

Some of the AAC users had attended transitional living programs. They felt however that these programs could not accommodate their unique needs as AAC users. They wanted the vocabulary and strategies they needed to direct their services and the time and opportunities to practise using them. They also wanted to learn how to train new attendants to communicate with them and how to compensate for the slow speed of their communication

systems. They wanted to learn about their human rights; what to expect from a service agency; how to negotiate a service contract or make a change within a contract. They wanted practical, pertinent information and resources. And they wanted this information to reflect their own unique challenges as users of AAC.

Over the twelve weeks, we used a combination of lecture, discussion, resource sharing, role play, and videotapes to cover the topics listed below.

Development of individualized service plans

Service plans explain what a person wants done and how he or she wants it to be done. For AAC users these plans can be critical in that AAC users may not have the time to communicate every detail of how they want their routine services to be given to them. Having documentation which illustrates how an AAC user wants to be assisted in transferring, eating, drinking, dressing etc. can become the cornerstone for AAC users in directing their own services.

Sample plans were developed as a group and each participant wrote up their own plans. The diversity of these plans was striking. For many of the participants, this was the first time they had ever tried to explain exactly how they wanted things done. Some admitted that they sometimes got frustrated with their attendants and how their services were being given to them. They came to realize however that they, the AAC users, had a responsibility in knowing and describing the details of their own service needs.

Teaching attendants to communicate with an AAC user

Participants reported that they had never received any training in this area. They reported that typically a familiar partner or clinician demonstrated how they communicated to the agency manager or to one or two attendants. This did not carry over however to other staff or to new staff. The AAC users wanted to be more independent in recognizing and identifying specific communication problems and in learning how to give constructive feedback to address these problems.

Each participant received valuable feedback from the group following a role playing exercise. The exercise required them to describe how they communicate with an unfamiliar partner. They spent time watching role play scenarios and identifying the differences between an attendant who doesn't know how to offer choices, ask questions or "read" what an AAC user communicates and one who knows how but chooses not to use these techniques. Different approaches addressing these issues were discussed. Some participants discovered that they tended to "jump to conclusions" and become frustrated with an attendant rather than stepping back and questioning whether they could give constructive feedback.

Communicating in specific contexts.

Vocabulary and communication strategies were shared and discussed for a range of situations. These included: dressing; transfers; bowel and bladder care; bathing; dental, nail, skin care; repositioning in bed/chair; grooming; food preparation, house-keeping, laundry, shopping; phone management; medication; wheelchair and adaptive equipment maintenance; communication system maintenance, etc. Each participant received com-

munication displays for these contexts which they customized for their own use or programmed into their devices.

Communicating with unfamiliar people

Participants identified some typical problems and brainstormed together on what to do about them. One was when an attendant speaks for the AAC user. A second was when a person speaks directly to an attendant and ignores the AAC user. A third was when the attendant does too much or too little when accompanying an AAC user to a meeting or translating over the phone.

"They wanted to learn about their human rights; what to expect from a service agency; how to negotiate a service contract or make a change within a contract. They wanted practical, pertinent information and resources."

Negotiating service contracts

Tim Kinney, from the OFCP, joined us for a session on human rights and what consumers can expect to get from their service agencies. It was interesting that only one of the participants had actually received a copy of the service contract he had with his service agency. When participants did get their service contracts they brought them to the course for discussion. At that time we realized that most of the contracts were not in a format that the AAC users could read or understand. So, we went through them. We learned what a contract should contain and what a client can negotiate with an agency. We learned about Ontario's Long Term Care Act and the rights which a consumer has under this Act. There were some interesting surprises. One participant discovered that his attendants were contracted to cook for him and he never knew that!

So, what did we all learn?

The AAC users unanimously report that they learned a great deal. They told us that they will be writing up their service plans for months to come but that this exercise is good as it focuses them on defining exactly what they want. Three of them want more support in following through with their attendants and have requested home visits to assist them. They all wanted more practice and role playing. A number of AAC users felt the course needed to be spread out over a year and to include such topics as assertiveness, conflict resolution, negotiating service contracts, teaching attendants, dealing with new attendants, recognizing and reporting abuse, and handling feelings. Many thought it should be offered to young adults in preparation for moving out of home.

For myself, I learned a great deal about the challenges of speaking-people in directing services for AAC users. I learned to respect the complexity and fragility of consumer/attendant relationships. I learned the frustrations of AAC users when their attendants ignore or reject their efforts to establish control in their lives. I reaffirmed my belief that successful communication is a two way street — both partners must play a role in making it happen. I think we must support this by advocating that attendants receive basic training in how to communicate with AAC users and that AAC users obtain the tools and skills they need to direct their services and communicate with their attendants. Throughout this course, I saw how AAC users can do a great deal to enhance their communication with their attendants and ultimately the quality of their lives.

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If you are interested in hosting a course on "Communicating with Attendants" in your area, you can contact Barbara Collier at 416-778-5460 or via email at bbbc@total.net

ALDA STEPRANS



Alda Steprans

I really should feel an expert on the subject of change. Observing, recording, evaluating change, is what my job as a nurse is really all about. And yet, I had not thought about my work in these terms before. Sometimes the changes I watch for are very little ones. When I listen to a patient's chest with a stethoscope, a small change in noise can alert me to a pneumonia, or heart disease. At other times I look for very noticeable changes. For example, when someone is bleeding and I apply pressure to the cut, I watch for whether the bleeding stops or not. Change and life are interlinked. Being born, childhood, adolescence, adulthood, aging and each day in between, all involve change. Some of these changes are sudden and immense. Who is not amazed by the processes of birth and death? Some changes are slow and steady. We don't see how a baby learns to understand language or walk, but over those first years of life a child, usually bit by bit, develops many skills.

We often look forward to change. Although I enjoy my job very much, I couldn't wait for my vacation this year. Going home to meet my family seemed like the most wonderful experience in the world. Yet, I distinctly remember that as a teenager, I longed to leave my home and travel far away.

Although we often enjoy change, there are times we simply dread it. I think we especially hate it when there is little control over it. I know the residents in the chronic care residence I worked in often disliked new care givers. Even though they enjoyed seeing a new face, they were not as receptive, if that inexperienced (with them) person was about to provide service to them. Would the person behind that face really care, really listen, really know how to make them comfortable? When I was doing community nursing, I had a patient who was afraid of becoming more independent, afraid of being able to care for herself now that she was no longer so ill. She was afraid of getting well because that would mean she would lose her homemaker, a person she had come to know well during her illness. Illness itself is a change no one enjoys.

I suppose it's small comfort to those who are experiencing unpleasant changes to be told that these changes may provide experiences for growth, for learning. But, I certainly believe this is so. I have watched people who have undergone massive changes in their lives come out of them changed, often stronger, if not in body, then in mind.

How can we help someone undergoing change, especially unpleasant change? We often feel so small and powerless in the face of it. It may sound simple, but I have found that offering support, simply being there, listening, reaching out, not running away or ignoring the situation can be very helpful in assisting others get through changes. One thing that constantly amazes me is the ability of people to adjust to change, to learn, to overcome. Adjusting to change often takes a lot of time. It helps for all involved to be patient.

I have had many incredibly gifted colleagues and teachers who have assisted me to change and to grow, professionally. But, my patients have also been very important in teaching me, in helping me to grow and change. Having watched my patients meet the challenges of the many changes in their lives has been truly inspiring. Audrey McGee and Steven Hanlon my coauthors are two such people, but there are many more. They may at first glance seem incapable and ill, but in having come to know them, I do not pity them. They have overcome so much in life. They enjoy and truly live life to its fullest. I admire them very, very much.

§

Change Itself Keeps Me Happy

STEVEN HANLON

Some things never change. I still love beer and the Minnesota Vikings! Really. I do believe that nothing has changed. I'm still crazy — I'm always very happy. I've always felt happy about life. But, there have been some changes in my life. My mum and dad died — so did my

grandmother and grandfather. My uncle died too. My wife's father died too. I miss all of these people. They were important to me.

I think change is good. Change itself keeps me happy. I never feel bored — I'm always too busy. But, thank God there's always beer around. Audrey, my co-author for **Communicating Together**, got me two beers not long ago. I drank one to celebrate the New Year.

If I hadn't gotten Huntington's, I would never have met Audrey and my other friends here, like Bruce. I

would never have come here to live in the hospital. The meals here are great! I still love eating. That will never change.

Having Huntington's Disease has been an enormous change in my life. I can't drink as much beer as I used to. I also can't eat the way I used to. I have an ulcer now. I can't eat pizza, MacDonalds meals or Chinese food and I miss that. I do love all the food they give me here. I really miss chocolate chip cookies, but here I get to enjoy lots of ice cream!

§

AUDREY MCGEE

Over the years, there have been many changes in this building that I live in. I cannot see out of its windows when I sit in my wheelchair. This building used to be a school and the windows were built high to help prevent students from becoming distracted from their work. But, they're not very useful for the disabled people who live here now

and get around by wheelchair. I miss seeing what is happening outside, especially in the winter when I cannot get out in the garden.

I used to live in another hospital that had beautiful windows all around but I didn't like the care I got there. People there seemed distant. Even though there aren't lovely windows here, I prefer to live here where people care about me. Life isn't perfect. It's always full of changes. We have to make decisions about life every day.

The government wants to close this hospital, my home. I know people here are working hard to try to keep it open. I don't worry about the closing too much. There is not much I can do to change things. I really have to take each day as it comes. If the hospital does close, I'll have to move and live somewhere else. But I do like it here very much.

Keeping busy makes it easier for me to accept changes. People's attitudes can make change easier to deal with. It helps to have friendly people around.

§

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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My Two Shadows

PAUL MARSHALL

Did you ever think of your life as a shadow? A shadow that is here today and gone tomorrow and only viewed by a few people on a sunny day. Do we have a shadow at night? We can't see them but we are still alive. There fore our shadows are still with us.

Like most of my columns, I swing toward writing about the energy that I believe everyone has in the inner person to master trials on the inside.

As I go through the lifelong process of dealing with changes, I am forever noticing there are two shadows with me. One is Paul Marshall. He has a history, a present and a future. He fails at things and when he is blessed, sometimes he wins at things. He is Paul and he has all the baggage that comes with that name. There are times when he would like to run away from his shadow but that is impossible to do. My other shadow is a something which is far greater than myself. It guides and shapes my life. No, I can't see or touch it, because it is spiritual. It is there for anyone to tap into and feed upon everyday, if we choose this overflowing source.

I often like to go for a walk in the woods and see the sun coming through the trees, making all kinds of shadows. They are always changing because of the movement of the sun. Life is a shadow. Life is dependent on things forever flowing, never staying the same. I remember in one of my past columns, I wrote that we as human beings must be ready and willing to welcome change into our

lives. If we aren't then we can't take the full enjoyment of the journey through life. Many of these circumstances are not easy to go through. I know myself, I can stay doing the same thing with the same people in the same place year in and year out, liking it. Probably most of us are like this. We get used to living the same life day in and day out. We know where the physical or mental holes in our routines might be that we need to jump over. I will give you an example.

When my parents drove down our stony old road, they knew where the holes were and which ones they could hit and which ones they couldn't. When our road was paved, we went the same direction on it but the holes were no longer there. Change had happened. The old way had to give way to the new. It goes without saying, the roads of our lives that we travel on are forever developing holes and bumps. When we fix one, another one or more appears.

Dealing with change is a fact of life which we have to accept. Some might say that we don't have to be happy with bad or unwanted changes that occur. In the long run however, we must be because our sadness will eat away at us. Note that I first talked about change in a negative way. Often we view any change negatively. As I look back through my years however, the changes that I viewed as bad events turned out ultimately to benefit me. Sure there were some bad times to go through. But they were common pot holes in life's journey. We never celebrate the process change. Why is this? I am convinced in order not to have things changing means being six feet under the ground.

Yet, when it comes to having a positive mind-set about things that are swaying and flowing, we throw up our hands and want things to remain the same forever. Moreover, many changes are out of our control. This is particularly true for anyone who has a disability. For this person, the number of out-of-control changes is multiplied many times over. There are many examples: Aging parents or care-givers can cause a disabled person's lifestyle to turn up-side-down; government cutbacks can create feelings of helplessness and even hopelessness; The countless daily struggles that some of us must face because we have to depend so much on others.

How can we face our tomorrows when so much is out of our hands? In my opinion, we need to do a couple of very very important things. Get to know your two shadows that you see each day. Talk to them and get to know them inside and out because your shadow(s) will change but they will be with you throughout this life. Know their strengths and weaknesses. Learn how to tap into their resources and learn how to fill them again with joy. No matter what changes the storms of life throw at you, the two shadows will be with you. They know you, but do you really know them?

I will leave you with this thought. View each day as your whole life. When you see the sunrise, think on the day as a new beginning. As you walk through the new day, do it as a peace keeper in the world. Do not desire to put yourself in the front. Be a server. Be a hearer and learner so you can be a doer of life. When you see the sunset, know that you have received because you have given.

§

Is the Change Positive?

SHIRLEY McNAUGHTON

When we first identified "Dealing with Change" as a theme at our editors' planning meeting a year ago, my thoughts flew to the AAC users I have met whose communication competencies have shown little indication of growth over the years. Of course, the individuals themselves have changed. They have grown taller, their living situations have altered dramatically as they moved from family, to group home or to independent living situations. The only noticeable change in their communication systems, however, has been the wear and tear on their boards or books. They have had no additional vocabulary or new strategies introduced. Nor has there been any evidence of progress to more advanced symbols.

I thought, as well, of those individuals I knew as children, who began promisingly — creating sentences independently with Blissymbols. Upon meeting them as adults, I sometimes found them using a picture board or a preprogrammed voice output communication device, demonstrating neither increased language skills nor improved literacy abilities. Whenever I met these AAC users, I felt disappointment for them and for their caregivers as I thought of their many missed learning opportunities. Would any speaking person wish to remain with the same or a reduced speaking vocabulary and their early fledgling literacy abilities as their teenage years passed by or as they moved from their teens through their twenties and thirties?

I have long ago realized that in AAC there is more to "dealing with

change" than moving to the latest technology or the newest symbol set. Except for those AAC users who have a regressive disorder and for whom special considerations must be made, I evaluate the way in which an individual has dealt with change by asking two questions: (1) Has the individual progressed toward more advanced capabilities? (2) Has the individual gained increased control over the decision-making related to his or her environment in general and to his or her communication system in particular? For these two questions to be answered positively, I have found that two conditions need to be met. First, the AAC user and those associated with him or her must have been able to access information concerning *what is possible*. Second, they must have acquired knowledge of *what constitutes positive change*.

I am reminded of my "dynamic integration growing model", described back in 1990 in my Phonic Ear lecture. The name is cumbersome, but I still believe the concept has merit.

Dynamic Integration Growing Model

The service delivery model of which I dream requires the flexibility of all members of the clinical team to continuously reorganize their support, adjusting their involvement as AAC users grow and their capabilities change. For preschoolers, the *speech pathologist*, *occupational therapist*, and/or *physiotherapist* would collaborate with the *parents*. As the child approaches nursery and preschool, the *parents* and *teacher* would assume primary responsibility, consulting with the *speech pathologist*, *occupational therapist*, and *physiotherapist* as necessary. In the primary years, the *teacher* would take responsibility for the academic

program and would integrate communication with all the other language/cognitive/literacy related activities of the beginning school years, while *parents* would coordinate the many supportive disciplines contributing to the child's development. By early adolescence, *students* themselves would gradually be taking more control, preparing for high school, when, hopefully they would make decisions, with help as needed from their *parents*, regarding which specialists they wish to consult. By the end of high school, the *AAC users* should be in full control of decision-making regarding their communication system, contacting specialists as required. I suggest this non-medical model, recognizing it has potential only for the growing AAC users. If we are striving toward independence of the individual, then members of the AAC team can best serve that goal through altering their roles as the AAC user's capabilities develop. Thus, growth and change in the individual requires growth and change in our model of service delivery. Every professional who is involved will benefit. The greatest growth of all comes from supporting the new independence of another — as every parent knows.

McNaughton, 1990, p. 11

I wish I saw this model being enacted more often!

What is Possible?

In former days, information concerning the possible (what can be done with the lite and high technology that is available) had to be obtained from professional journals and conferences, manufacturers' catalogues, AAC clinics, etc. These sources of information still exist. Now however, there are additional opportunities for AAC users and their caregivers to access information independently,

using the Internet. Here are just a few of the websites currently providing information regarding AAC.

Ablenet inc.
www.ablenetinc.com

Adaptivation Incorporated
<http://users.aol.com/adaptaac>

Assistive Technology, Inc.
www.assistivetech.com

Betacom Group and Bridges
<http://www.betacom.com>

Blissymbolics
<http://home.istar.ca/~bci>

Discover & Icon Galleries
www.donjohnston.com

Mayer-Johnson Co.
www.mayer-johnson.com

Prentke Romich Company
www.prentrom.com

Toby Churchill Ltd.
www.toby-churchill.demon.co.uk/

Widgit Software www.widgit.com

Words Plus
<http://www.words-plus.com>

ZYGO
www.zygo-usa.com

**International Society for
Augmentative and Alternative
Communication (ISAAC)**
www.isaac-online.org

ACE Centre in Oxford, England
[http://www.rmplc.co.uk/eduweb/
sites/acecent/index.html](http://www.rmplc.co.uk/eduweb/sites/acecent/index.html)

**MicroCentre Dept. of
Mathematics & Computer Science,
University of Dundee, Scotland**
<http://www.computing.dundee.ac.uk>

Those knowing of other sites providing information for AAC users are invited to send them to **Communicating Together**. We will be pleased to publish them.

What is Positive?

What constitutes progress and advancement? To respond to this question, the AAC user and those involved with his or her communication need first to have a basic understanding of the competencies involved in *communication, language and literacy*. And they must know how these competencies are developed.

Communication Competencies

In 1989, Janice Light proposed a definition of communicative competence for persons using AAC systems that has been widely accepted by the AAC field. It directs our attention to the critical areas involved in their successful communication. She described communicative competence as "relative and dynamic". According to Light, our abilities are based in four interrelated areas.

The first area is that of *linguistic* competence. For AAC users this means mastering the conventions of their native language as spoken by those around them. It also means mastering the "linguistic" code of their AAC system. The unique communication of AAC users involves "*receiving*" communication in one mode, through the input spoken by others and "*expressing*" ideas through another mode, that of their AAC system. For AAC users, the linguistic demands extend far beyond those of speakers!

The second area is that of *operational* competence. This includes the technical skills required to operate the AAC system. To communicate successfully, AAC users must master the motor, perceptual and cognitive demands of a high tech. voice output device/computer, or of a lite tech. communication board/book. Here

again, AAC users have additional demands placed upon them as compared to speakers.

The third area identified by Light is that of *social* competence. This requires the knowledge that comes through many opportunities to interact with a variety of persons. The AAC user must learn to initiate, maintain and end a conversation, to take turns, to express needs and wants, to exchange information, to express ideas in ways that are appropriate to the partner and the situation. The young speaking child acquires these social skills gradually through many interactions with a wide range of persons in many different settings. AAC users do not typically have the same number or range of experiences as their speaking counterparts. Thus, in this area again the challenges are greater for AAC users.

The fourth competence area is that of *strategic* competence. Here once more, AAC users are faced with unique challenges. Often the AAC system cannot say what they want in the way they want. They must take advantage of strategies within their communication systems and as well develop personal strategies to allow them to express their ideas effectively.

Gaining knowledge within these four competency areas and being able to improve one's skills in each of them is critical to change that is positive for the AAC user. They and those with whom they interact must continually be asking how well the communication system, both its high and lite technology components, contributes to the above competencies. If the system does not support growth in all of these competency areas, then there is a strong argument to be made that the change being introduced is not positive.

Language Development

The metaphor of the "language pathway", as described in the September, 1992 *Symbol Talk* provides possibly the simplest description of language development. One can picture the language pathway of AAC users as consisting of five strands — *visual, social, auditory, motor* and *symbolic*. All of the strands develop independently but there are many interactions between them. One can see the results of development within the motor strand resulting eventually in the operational competency described by Light. Development in the social strand leads to social competency. Both the visual and the auditory strands contribute to linguistic competency, as skills are developed in both the AAC graphic system used for expressive communication and the spoken language relied upon for receptive communication. Development along the symbolic strand nurtures both linguistic and strategic competencies.

Climbing the Literacy Ladder

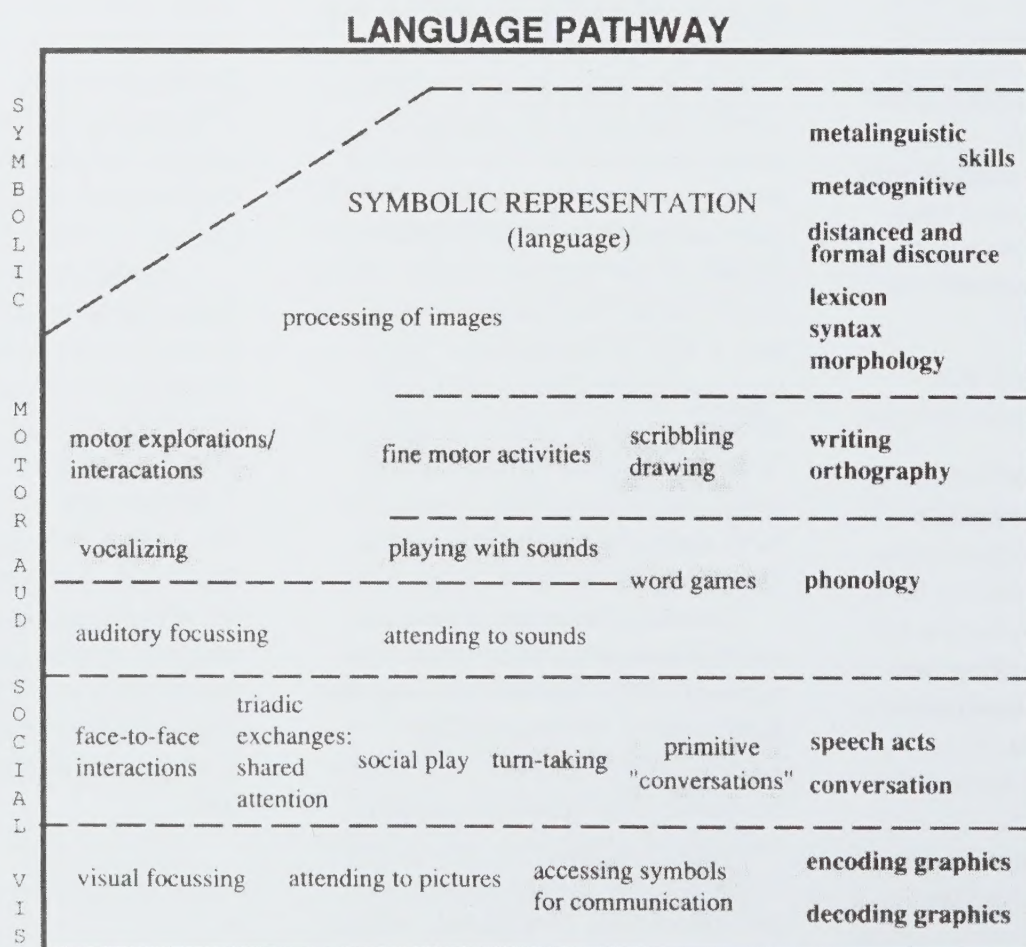
My description of the literacy ladder in the last issue of **Communicating Together** offers a metaphor for literacy development. Progress in literacy occurs as the AAC user climbs from the reading and (computer) writing of pictures, to the reading and (computer) writing of Blissymbols, to the reading and (computer) writing of words. In a future article, I will describe the progression from holistic processing to analytic processing that takes place as the literacy ladder is climbed. As we consider dealing with change in ways that support advancement and progress, it is important to remember that conscious analytic knowledge is critical to the successful independent reading of print. Advancement from the recognition (*holistic* processing) of pictures, to the semantic analysis of Blissymbols, to the phonological analysis of words is the kind of change we need to support. Returning to my previous metaphor,

remember as well that all the strands of the language pathway contribute to literacy competency just as they do to communication competency.

Dealing with Change

What must be done after knowledge of the possible and knowledge concerning language, literacy and communication development have been acquired? A simple but not easily achieved next step is needed: *Evaluate the AAC user's communication system on an ongoing basis*. This evaluation should in turn be based on answers to the following questions: (1) Is it changing in ways that support the individual's personal growth? (2) Is it enabling the individual to deal with changes in his or her life situations?

In the current world of reduced services and resources for persons with disabilities, regular reviews and upgrading of communication systems is much easier said than done. Yet we must find ways to enable the communication systems (and the resulting



communication, language and literacy competencies) of all AAC users to grow. We must not be satisfied with working with just the lucky ones who manage to gain a place on a waiting list and eventually receive service from an AAC clinic or professional. I admire so much those individuals assisted by family, friends and caregivers who find ways to make improvements to and become managers of their communication systems. It is a skill that every AAC user should acquire. In the early days of Bliss, we had a place on the Bliss board that said, "Please I would like a symbol for —". It should be an expectation of every AAC user that their communication system will be upgraded to meet their changing needs. Our challenge is to see that the expectation is fulfilled!

I am always amazed at the patience of AAC users. I have witnessed situations in which the changes to a communication system have taken over two years to implement. The individuals have quietly waited until all the arrangements could be made. I have recently learned of a child who is receiving no communication system beyond personal gestures while funding for a high tech. device is being sought. Lacking knowledge of *what is possible* with regard to manual communication boards and/or signing, the child and her parents wait (too) patiently! Early developmental years are being lost because the family is not aware of the value to be derived from the lite tech. components within an individual's AAC system. In other situations, in which individuals have "been changed" to communication systems with lower capabilities, knowledge of what constitutes advancement has been lacking on the part of both the caregivers and the AAC user. And they have passively settled for the newest and latest even though it may offer fewer independent communication capabilities to the user

and reduced opportunities for language and literacy development.

What happens when there is no constructive change made to an individual's communication system? AAC users are deprived of adequate communication tools to deal with their own growth and their changing life situations. We should not be surprised to witness frustration, depression or apathy. I am always saddened when I meet AAC users who have fallen between the cracks and who have lived for many years with the same system or who have had changes made to their systems by those with limited knowledge, with little input from the AAC user. In contrast, it is so reassuring to see AAC users who have received AAC systems as a result of the knowledgeable service provided by skilled members of an AAC professional team in which the AAC user has participated as a member, or to see AAC users with communication systems developed by knowledgeable families, friends and caregivers responding to an AAC user's determination to advance.

A Note of Caution

In spite of all that I have just said, we cannot take for granted that all change to a more advanced system is good. I remember vividly a talk given by Gregg Vanderheiden in the late seventies. As one of the early leaders in the area of AAC assistive technology, Gregg was quick to recognize the sometimes seductive power of the latest device. In his talk he compared communication devices to automobiles. He first asked his audience to raise their hand if they would like a new car. Not surprisingly, nearly everyone put up their hand. Then he asked if they would want a new car, if it meant learning how to drive all over again. The number of hands were greatly reduced. He also discovered through further questioning that there were many persons present who, upon thinking about it, felt their current car "fitted them well". They saw no need

to change. Gregg illustrated well the lesson that we can often be very ably served by a less than latest model. And the same can be said of a voice output device or a computer. The latest model may not always be the best for a particular individual, especially if it comes with many new operational demands. There is something comfortable about using a familiar device with which we have had long association. We do need to obtain regular tune-ups, however, and we need to know when the "car" is no longer roadworthy. Above all — we have to ensure that the decision to remain with a less advanced model is an *informed* one and is being made *by the user*. §

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